

GIVING VOICE TO A SILENT DISORDER: A POLICY PROPOSAL TO ADDRESS
POLYCYSTIC OVARY SYNDROME

by
Erica Nash-Thomas

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ABSTRACT

On July 8, 2020, the U.S. Supreme Court upheld a Trump Administration rule limiting the birth control benefit, including oral contraceptives, under the Affordable Care Act, which would permit employers to refuse coverage in their employee health plans on “moral or religious” grounds. The ruling threatens access to this medicine to the millions of women and girls living with Polycystic Ovary Syndrome (PCOS), a hormonal, metabolic and reproductive disorder. PCOS affects between about five to 10 million women and girls in the United States, and more than 50 percent of women living with PCOS are either unaware they have the disorder or are improperly diagnosed. The exact cause of this incurable disorder remains unknown.

This Capstone explores the history of PCOS, its classifications over the years and the ways that activists and advocates have organized to raise awareness about the disorder. The paper will present the soundness of pursuing a legislative remedy that would give voice to a silent disorder affecting the health outcomes of millions of women (and African American women more severely), with an estimated total annual cost of at least \$4 billion in the United States. The Capstone also provides an examination of a legislative proposal that would protect the medicines women and girls need while expanding research, encouraging the development and training of more PCOS researchers and promoting public education about the disorder.

Advisor: Professor Paul Weinstein

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MEMORANDUM

To: Representative Karen Bass, Chairwoman, Congressional Black Caucus

From: Erica Nash-Thomas

Date: September 20, 2020

Subject: Giving Voice to a Silent Disorder: A Policy Proposal to Address Polycystic Ovary Syndrome

I. Action-Forcing Event

On July 8, the U.S. Supreme Court upheld a Trump Administration rule limiting the birth control benefit under the Affordable Care Act (ACA) in a 7-2 decision. The case, *Little Sisters of the Poor v. Pennsylvania*¹, allows employers to refuse this coverage in their employee health plans on “moral or religious” grounds.

II. Statement of the Problem

This ruling not only threatens the birth control coverage of millions of people around the country—amid a public health and economic crisis due to COVID-19—but also threatens access to oral contraceptives, which is a medicine that millions of women and girls living with Polycystic Ovary Syndrome use to treat their symptoms.

¹

Little Sisters of the Poor Saints Peter and Paul Home v. Pennsylvania, 591 U.S. ____, (2020)

Polycystic Ovary Syndrome (PCOS) is a hormonal, metabolic and reproductive disorder² affecting between 10-15 percent of women and girls,³ which is about five to 10 million women in the United States,⁴ with a worldwide prevalence of PCOS ranging from four percent to 21 percent.⁵ This disorder can occur at any age after the onset of puberty.⁶ It is one of the leading causes of infertility, and is the most frequent endocrine disorder for women of childbearing age.”⁷

John Nestler, Virginia Commonwealth University department chair of internal medicine, describes the current understanding of PCOS this way: “Classically, we thought of PCOS primarily as an infertility disorder or a cosmetic annoyance, but we now know that it’s also a metabolic disorder and a serious long-term health concern.”⁸ Given its prevalence, researchers are still just beginning to uncover the disorder’s full impact.”⁹ The exact cause of PCOS remains unknown, and the disorder is incurable.¹⁰

² PCOS Challenge: The National Polycystic Ovary Syndrome Association, “What is PCOS?” accessed on September 7, 2020, <https://pcoschallenge.org/what-is-pcos>.

³ Ibid.

⁴ U.S. Congress, House. *Recognizing the seriousness of polycystic ovary syndrome (PCOS) and expressing support for the designation of the month of September 2020 as “PCOS Awareness Month,”* H. Res. 972. 116th Cong, 2nd sess., introduced in the House on May 19, 2020. <https://www.congress.gov/bills/116th-congress/house-resolution/972/text?q=%7B%22search%22%3A%5B%22PCOS%22%5D%7D&r=1&s=1>.

⁵ Soumia Brakta, Daria Lizneva, Kateryna Mykhalchenko, et al., “Perspectives on Polycystic Ovary Syndrome: Is Polycystic Ovary Syndrome Research Underfunded?” *The Journal of Clinical Endocrinology & Metabolism*, Volume 102, Issue 12, 1 December 2017, Pages 4421–4427, <https://doi.org/10.1210/jc.2017-01415>.

⁶ Bremer, A. A. “Polycystic Ovary Syndrome in the Pediatric Population,” *Metabolic Syndrome and Related Disorders*, 8(5), 375–394.

⁷ Kyrou, I., Karteris, E., Robbins, T. et al., “Polycystic ovary syndrome (PCOS) and COVID-19: an overlooked female patient population at potentially higher risk during the COVID-19 pandemic.” *BMC Med* 18, 220 (2020). <https://doi.org/10.1186/s12916-020-01697-5>

⁸ Sydney Parker, “When Missed Periods are a Metabolic Problem,” *The Atlantic*, June 26, 2015, https://www.theatlantic.com/health/archive/2015/06/polycystic-ovary-syndrome-pcos/396116/?gclid=CjwKCAjw8MD7BRArEiwAGZsrBcuVLyJYQjSQvc32pqn7aShYWGfM5Cg0Ek202SPzpXYEop2BJfN0ORoCoUYQAvD_BwE.

⁹ Ibid.

¹⁰ U.S. Department of Health and Human Services, Office on Women's Health, <https://www.womenshealth.gov/a-z-topics/polycystic-ovary-syndrome#16>

While the estimated total annual burden of PCOS in the United States is estimated to be \$4.36 billion (using 2004 figures),¹¹ PCOS was significantly less funded as compared to disorders with similar or lower mortality and prevalence, according to a study published in *The Journal of Clinical Endocrinology & Metabolism*.¹²

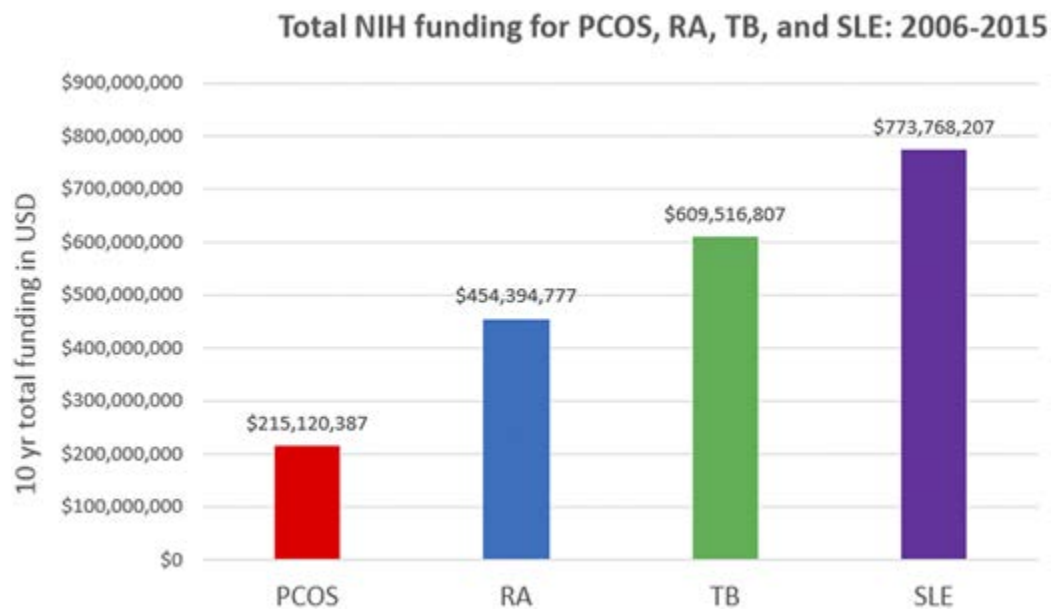


Figure 1. Total NIH funding for PCOS, RA, TB, and SLE: 2006 to 2015. USD, US dollars.¹³

Although PCOS is one of the most common female endocrine disorders, it seems it is a disorder that is hiding in plain sight of the public, and particularly for the people who may be affected by it. More than 50 percent of women living with PCOS—more than half—are diagnosed improperly.¹⁴

¹¹ Soumia Brakta, Daria Lizneva, Kateryna Mykhalchenko, et al., “Perspectives on Polycystic Ovary Syndrome: Is Polycystic Ovary Syndrome Research Underfunded?” *The Journal of Clinical Endocrinology & Metabolism*, Volume 102, Issue 12, 1 December 2017, Pages 4421–4427, <https://doi.org/10.1210/jc.2017-01415>.

¹² Ibid.

¹³ Ibid. Disorders referred to in Figure 1 are the following: rheumatoid arthritis (RA), tuberculosis (TB) and systemic lupus erythematosus (SLE).

¹⁴ “What is PCOS?” PCOS Challenge: The National Polycystic Ovary Syndrome Association. accessed on September 7, 2020, <https://pcoschallenge.org/what-is-pcos/>.

A 2017 study conducted by the University of Pennsylvania's Perelman School of Medicine showed that "... one-third of women diagnosed with PCOS saw at least three health professionals over the course of two years."¹⁵ Oftentimes, women do not discover or confirm that they have PCOS until they attempt to conceive.

Obstacles remain for PCOS women who wish to conceive because they have a higher risk of pregnancy and delivery complications. These complications include gestational diabetes and Cesarean section delivery.¹⁶ It also can lead to preeclampsia, a leading cause of maternal and infant death. Occurring after the 20th week of pregnancy, preeclampsia causes a sudden increase in blood pressure that develops "during pregnancy or the postpartum period," which can damage the mother's kidneys, liver or brain.¹⁷ The rate of preeclampsia in the United States has increased 25 percent, according to the Preeclampsia Foundation.¹⁸

Women with PCOS are more likely to undergo cesarean section delivery¹⁹ and are more likely to have premature births or deliver babies with low birth weight. Women with the disorder are three times as likely to miscarry as well.

¹⁵ Perelman School of Medicine at the University of Pennsylvania, "Two years, multiple doctors often needed to diagnose polycystic ovary syndrome, study shows," *ScienceDaily*, accessed on September 18, 2020, www.sciencedaily.com/releases/2017/01/170109191555.htm.

¹⁶ Black Women's Health Imperative Staff, "What Is PCOS? Understanding Polycystic Ovary Syndrome," Black Women's Health Imperative, August 1, 2017.

¹⁷ "What is Preeclampsia?" Preeclampsia Foundation, January 17, 2020, <https://www.preeclampsia.org/what-is-preeclampsia>.

¹⁸ Ibid.

¹⁹ Black Women's Health Imperative Staff, "What Is PCOS? Understanding Polycystic Ovary Syndrome," Black Women's Health Imperative, August 1, 2017, <https://bwhi.org/2017/08/01/pcos-understanding-polycystic-ovary-syndrome/#:~:text=PCOS%20affects%20women%20of%20all,cardiovascular%20disease%20or%20metabolic%20syndrome>.

Symptoms of PCOS extend beyond infertility, often leading to other health risks and diseases as well. For example, women with PCOS are at higher risk of obesity. Some studies suggest that PCOS women may have three times the risk for endometrial cancer and could be at increased risk for ovarian cancer and breast cancer.²⁰

Women with PCOS also have a greater risk of developing chronic diseases such as diabetes and cardiovascular diseases (including heart disease, high blood pressure, high cholesterol and stroke.)²¹ More than 50 percent of women with PCOS will become either diabetic or prediabetic before age 40, according to the National Institutes of Health (NIH).²² Research also suggests that these risks can extend well beyond childbearing years. Women with PCOS before menopause “... appear to have a greater risk of stroke, heart attack, and other cardiovascular events after menopause ...” according to findings presented during the American Society for Reproductive Medicine 2020 Scientific Congress.²³

Chronic diseases not only present physical costs to those who deal with the symptoms and effects of the diseases but also exact a high toll on the health care system. “Chronic diseases such as heart disease, cancer and diabetes are the leading causes of death and disability in the United States. They are also leading drivers of the nation’s \$3.5 trillion in annual health care costs.”²⁴

²⁰ PCOS Challenge: The National Polycystic Ovary Syndrome Association, “What is PCOS?” accessed on September 7, 2020, <https://pcoschallenge.org/what-is-pcos/>

²¹ U.S. Department of Health and Human Services, Office on Women's Health; “Polycystic Ovary Syndrome,” accessed on September 7, 2020, <https://www.womenshealth.gov/a-z-topics/polycystic-ovary-syndrome>.

²² U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, “PCOS (Polycystic Ovary Syndrome) and Diabetes,” accessed on September 7, 2020, <https://www.cdc.gov/diabetes/basics/pcos.html>.

²³ Tara Haelle, “PCOS Tied to Risk for Cardiovascular Disease After Menopause,” Medscape, October 19, 2020, https://www.medscape.com/viewarticle/939402?src=soc_tw_201021_mscpedt_news_mdsep_pcos&faf=1#vp_1

²⁴ Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion; “Health and Economic Costs of Chronic Diseases,” accessed on September 13, 2020, <https://www.cdc.gov/chronicdisease/about/costs/index.htm>.

PCOS affects mental health as well. Women with PCOS are more likely to battle depression, and some studies show that suicide attempts are up to seven times more common in women with PCOS than other women.²⁵ According to the National Institute of Mental Health, “Major depression is one of the most common mental disorders in the United States.”²⁶ Depression also carries a steep economic cost. A 2015 study found that the economic burden of suffering from major depressive disorders was \$210.5 billion in 2010.²⁷ This effect on mental health and physical health can be a longstanding one. According to a report released by the Endocrine Society, “Women with PCOS experience psychological issues like anxiety and depression that continue well beyond fertile age.”²⁸

PCOS is especially alarming for African American women. The disorder affects women of color more frequently and severely than white women. A team of researchers conducting a comparative study literally named their report, *Black women with Polycystic Ovary Syndrome (PCOS) have increased risk for metabolic syndrome and cardiovascular disease compared with white women with PCOS*²⁹ to delineate the health outcomes between African American and white women. African Americans have higher morbidity and mortality due to cardiovascular disease and diabetes and have greater hyperinsulinemia and insulin resistance—diseases and disorders

²⁵ PCOS Challenge: The National Polycystic Ovary Syndrome Association, “What is PCOS?” accessed on September 7, 2020, <https://pcoschallenge.org/what-is-pcos/>.

²⁶ “Major Depression,” National Institute of Mental Health, accessed on September 19, 2020, <https://www.nimh.nih.gov/health/statistics/major-depression.shtml>.

²⁷ Paul Greenburg, “Quantifying the Economic Burden of Depression,” accessed on September 13, 2020, <https://www.analysisgroup.com/Insights/cases/quantifying-the-economic-burden-of-depression>.

²⁸ “Women with PCOS experience poor health and quality of life beyond reproductive years,” Endocrine Society, January 23, 2020. <https://www.endocrine.org/news-and-advocacy/news-room/2020/women-with-pcos-experience-poor-health-and-quality-of-life-beyond-reproductive-years>.

²⁹ Jennifer Hillman, et al., “Black women with polycystic ovary syndrome (PCOS) have increased risk for metabolic syndrome and cardiovascular disease compared with white women with PCOS [corrected],” *Fertility and Sterility* vol. 101,2 (2014): 530-5. doi: 10.1016/j.fertnstert.2013.10.055.

also associated with PCOS. Also, African American women who wish to conceive often have less access to fertility treatments.³⁰

But danger lurks for African American women even if they successfully conceive: African American mothers are 243 percent more likely to die from pregnancy- or childbirth-related causes, which is “one of the widest of all racial disparities in women's health.”³¹ Given the effects of the disorder on its own, and the fact that PCOS functions as a multiplier for other health concerns such as chronic diseases and maternal death make the disorder particularly alarming.

Oral contraceptives are routinely prescribed to women and girls with PCOS to regulate menstrual cycles, which are often irregular or infrequent.³² This medicine can also be “... protective against ovarian and uterine cancers.”³³ Oral contraceptives also can induce regular menstruation for women and girls. This is crucial since endometrial cancer is linked to incidences of irregular or infrequent menses. Infrequent menses can result in endometrial hyperplasia which can develop into endometrial cancer. Women with PCOS are three times more likely to have endometrial cancer. Oral contraceptives, therefore, are often prescribed to help women with PCOS to prevent such an outcome from occurring.³⁴

³⁰ Lisa Marie Basile, “Why PCOS Affects Women of Color Differently?” accessed September 20, 2020. <https://www.endocrineweb.com/news/polycystic-ovary-syndrome-pcos/63344-why-pcos-affects-women-color-differently>.

³¹ Nina Martin and Renee Montagne, “Black Mothers Keep Dying After Giving Birth. Shalon Irving's Story Explains Why,” December 7, 2017, <https://www.npr.org/2017/12/07/568948782/black-mothers-keep-dying-after-giving-birth-shalon-irvings-story-explains-why>.

³² Hilda Hutcherson, “Polycystic Ovary Syndrome: What It Is, How to Manage It,” *New York Times*, September 20, 2020. <https://www.nytimes.com/article/polycystic-ovary-syndrome.html?auth=login-google>.

³³ Pamela Verma Liao and Janet Dollin, “Half a century of the oral contraceptive pill: historical review and view to the future,” *Canadian family physician Medecin de famille canadien* vol. 58,12 (2012): e757-60, accessed on November 11, 2020, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3520685>.

³⁴ Sydney Parker, “When Missed Periods are a Metabolic Problem,” *The Atlantic*, June 26, 2015, https://www.theatlantic.com/health/archive/2015/06/polycystic-ovary-syndrome-pcos/396116/?gclid=CjwKCAjw8MD7BRArEiwAGZsrBcuVLyJYOjSQvc32pqn7aShYWGfM5Cg0Ek202SPzpXYEo p2BJfN0ORoCoUYQAvD_BwE.

The repercussions that women and girls with PCOS face if they do not obtain oral contraceptives are real, and the health consequences can be severe. In 2012, a Georgetown University law student with PCOS attempted to use the health insurance provided by the university to cover the costs of the oral contraceptives she needed to manage her PCOS. Despite her doctor's diagnosis, her insurance claims for the medicine were denied repeatedly. She could not afford the medicine's out-of-pocket costs, so she stopped taking the medicine. Shortly thereafter, the student developed a large ovarian cyst. Both the cyst and ovary required surgical removal.³⁵

This is one reason among many that access to birth control, including oral contraceptives, must be maintained. This access already faced assault before the ruling. According to research from the Center for American Progress, "... between January 2014 and March 2016, more than half of the entities listed as requesting the birth control accommodation from the federal government were for-profit companies representing a variety of industries with a range in number of employees."³⁶ The ruling would seem to encourage and hasten this disturbing trend.

Indeed, the Commonwealth Fund reports that the ruling "... *immediately* deprives between 70,500 and 126,400 women access to low-cost contraceptives, and it could potentially affect 2.9 million more women insured through employers that could choose exemption."³⁷ (Emphasis mine.)

³⁵ Denise Grady, "Ruling on Contraception Draws Battle Lines at Catholic Colleges," *The New York Times*, January 30, 2012, <https://advance-lexis.com.proxy1.library.jhu.edu/api/document?collection=news&id=urn:contentItem:54VB-VS41-JBG3-654B-00000-00&context=1516831>.

³⁶ Shilpa Phadke, Jamila Taylor, and Nikita Mhatre, "Rhetoric vs. Reality: Why Access to Contraception Matters to Women," Center for American Progress, November 15, 2017, <https://www.americanprogress.org/issues/women/reports/2017/11/15/442808/rhetoric-vs-reality-access-contraception-matters-women/>.

³⁷ Timothy S. Jost, "Supreme Court Excuses Organizations with Religious or Moral Objections from Covering Workers' Birth Control," The Commonwealth Fund, July 9, 2020, <https://www.commonwealthfund.org/blog/2020/supreme-court-excuses-organizations-religious-or-moral-objections->

As has been demonstrated from the information presented in this section, PCOS severely affects the health outcomes of millions of women and affects African American women more severely. PCOS exacts a high cost to the country's health care system, as well as a high personal cost to the women and girls who live with the disorder. Finding a concrete way to combat PCOS is one way to keep fidelity to the CBC's commitment to a policy agenda³⁸ to improve health outcomes by decreasing the health disparities that African American women face.

III. History and Background

The earliest known discovery of what would become known as Polycystic Ovary Syndrome can be found as early as 1721. Other early studies on the disorder were made in 1844, 1872, 1902 and 1910.³⁹ It was not until the report, "Amenorrhea Associated with Polycystic Ovaries,"⁴⁰ authored by Irving Freiler Stein and Michael Leventhal and presented at the Central Association of Obstetricians and Gynecologists in 1935 that the disorder was more comprehensively described and defined.⁴¹ Their report is considered to be a seminal one.⁴² The disorder would soon become known as Stein-Leventhal Syndrome; references to PCOS as Stein-Leventhal Syndrome are still easily found in medical and academic journals and from search engines. At the time of the 1935 report and for some years after its publication, Stein-Leventhal Syndrome was considered to be a rare disorder.⁴³

[covering-workers-birth?gclid=CjwKCAjwrKr8BRB_EiwA7eFappCfeNpkkIRihQacRALxsCqnjo01MeknVrpp7-oQW6MzeodMiIydyRoC9g8QAvD_BwE.](https://www.congress.gov/legislation/bills/115/1007/978-1-59745-179-6_1)

³⁸ Congressional Black Caucus (CBC), accessed on September 20, 2020, <https://cbc.house.gov/about/agenda.htm>.

³⁹ Ricardo Azziz, (2006) A Brief History of Androgen Excess. In: Azziz R., Nestler J.E., Dewailly D. (eds) Androgen Excess Disorders in Women. *Contemporary Endocrinology*. Humana Press. https://doi-org.proxy1.library.jhu.edu/10.1007/978-1-59745-179-6_1

⁴⁰ Ricardo Azziz and Eli Y. Adashi, "Stein and Leventhal: 80 years on," *American Journal of Obstetrics & Gynecology*. Published: December 16, 2015, DOI: <https://doi.org/10.1016/j.ajog.2015.12.013>

⁴¹ Cindy Farquhar, (2007), "Introduction and history of polycystic ovary syndrome," In G. Kovacs & R. Norman (Eds.), *Polycystic Ovary Syndrome* (pp. 4-24). Cambridge: Cambridge University Press. doi:10.1017/CBO9780511545191.002

⁴² Ricardo Azziz and Eli Y. Adashi, "Stein and Leventhal: 80 years on," *American Journal of Obstetrics & Gynecology*. Published: December 16, 2015, DOI: <https://doi.org/10.1016/j.ajog.2015.12.013>.

⁴³ Ricardo Azziz, (2006) "A Brief History of Androgen Excess. In: Azziz R., Nestler J.E., Dewailly D. (eds) Androgen Excess Disorders in Women," *Contemporary Endocrinology*. Humana Press. https://doi-org.proxy1.library.jhu.edu/10.1007/978-1-59745-179-6_1

Stein and Leventhal's research has spawned many names and references in medical literature over the years, including "... polycystic ovaries disorder, a syndrome of polycystic ovaries, functional ovary androgenism, hyperandrogenic, chronic anovulation, polycystic ovarian syndrome, ovarian dysmetabolic syndrome, sclerotic polycystic ovary syndrome, polycystic ovary syndrome."⁴⁴ The disorder became known as "PCOS" as the understanding of the disorder deepened, although the literature is not determinative on precisely when the disorder became known as PCOS.

Perhaps owing to the many references to the disorder, its "heterogeneity" and the "prevailing conflicts in published studies"⁴⁵ regarding PCOS, the first international conference of PCOS was held at NIH⁴⁶ to recommend formal diagnostic criteria were proposed. These criteria became known as "the NIH criteria" and "received large scale of acceptance in the research and clinical communities."⁴⁷

In 2003, doctors, researchers and other experts took another step to further refine the understanding of PCOS and expand criteria to properly diagnose the disorder. In 2003, the disorder's diagnostic criteria were expanded into what would become known as the "Rotterdam criteria."⁴⁸ These guidelines were accepted by organizations such as the European Society for Human Reproduction and Embryology and the American Society for Reproductive Medicine, and have been widely adopted and accepted by most doctors and specialists.⁴⁹

⁴⁴ Dorota Szydlarska, Małgorzata Machaj and Artur Jakimiuk, "History of Discovery of Polycystic Ovary Syndrome," (2017). *Advances in Clinical and Experimental Medicine*, <https://doi.org/10.17219/acem/61987>

⁴⁵ Ricardo Azziz, "PCOS: A Diagnostic Challenge," Reproductive BioMedicine Online, April 5, 2004, www.rbmonline.com/Article/1274.

⁴⁶ Rui Wang, and Ben Willem, "The Rotterdam criteria for polycystic ovary syndrome: evidence-based criteria?" *Human Reproduction*, Volume 32, Issue 2, 1 February 2017, Pages 261–264, <https://doi.org/10.1093/humrep/dew287>

⁴⁷ Dorota Szydlarska, Małgorzata Machaj and Artur Jakimiuk, "History of Discovery of Polycystic Ovary Syndrome," (2017), *Advances in Clinical and Experimental Medicine*, <https://doi.org/10.17219/acem/61987>

⁴⁸ Ibid.

⁴⁹ Ibid.

Interest in PCOS can be found in some medical literature. One report describes that interest in this way: “Since the classical observation of Stein and Leventhal in 1935, interest in polycystic ovaries and its associated syndrome [PCOS] has evolved from a ‘gynaecological curiosity to a multisystem endocrinopathy.’” The article goes on to say that “evidence of the ongoing interest in this disorder is not difficult to find; an electronic search on Medline from 1966 to 2005 using the search term ‘polycystic ovary syndrome’ produces 5112 citations; 934 are review articles, and 200 are randomized controlled trials (Fig. 2.1), and the majority of publications occur after 1985.”⁵⁰

Another article refers to the “exponential interest” in PCOS. “The 50 years between 1950 and 2000 saw a little more than 8000 publications on the topic, whereas the 15-year period between 2001 and 2015 (so far) has seen more than 20,000 related publications, a greater than 8-fold increase in the publication rate after 2000.”⁵¹

A survey of PubMed, a database managed by the National Center for Biotechnology Information, references 69 articles published referencing “polycystic ovary syndrome” or “Stein–Leventhal syndrome” in 1980; 169 articles in 1990 and more than 241 articles in 2000.”⁵²

While measurable increases in PCOS references in the medical literature may have occurred, PCOS remains a cross-discipline disorder, which makes researching answers more

⁵⁰ Cindy Farquhar, (2007), “Introduction and history of polycystic ovary syndrome.” In G. Kovacs & R. Norman (Eds.), *Polycystic Ovary Syndrome* (pp. 4-24). Cambridge: Cambridge University Press. doi:10.1017/CBO9780511545191.002

⁵¹ Ricardo Azziz and Eli Y. Adashi, “Stein and Leventhal: 80 years on,” *American Journal of Obstetrics & Gynecology*. Published: December 16, 2015, DOI: <https://doi.org/10.1016/j.ajog.2015.12.013>

⁵² Ricardo Azziz, (2006), “A Brief History of Androgen Excess,” In: Azziz R., Nestler J.E., Dewailly D. (eds) *Androgen Excess Disorders in 44 Women. Contemporary Endocrinology*. Humana Press, https://doi-org.proxy1.library.jhu.edu/10.1007/978-1-59745-179-6_1

difficult. Although the Rotterdam criteria have been widely accepted among doctors, specialists and researchers, “PCOS does not have a single diagnostic marker to provide a gold standard for reference.”⁵³

Daniel Dumesic, a reproductive endocrinologist at Ronald Reagan UCLA Medical Center, points to the disorder’s many complexities for the dearth of PCOS specialists and researchers. “When any condition crosses disciplines and doesn’t have a full investment in [one of them], it often falls through the cracks. There are elements of reproduction in PCOS, but most reproductive endocrinologists mostly do in-vitro fertilization and are not necessarily interested in metabolism. Medical endocrinologists, who are mostly interested in metabolism, aren’t usually interested in reproduction and ovarian function.”⁵⁴

PCOS news coverage has increased over the years, which is important way to help build awareness of the disorder among the public. A Nexis Uni search found only five news stories referencing PCOS from 1980 to 1989. That number would increase to 15,358 news stories about the disorder from 2010 to 2020.

⁵³ Rui Wang and Ben Willem, “The Rotterdam criteria for polycystic ovary syndrome: Evidence-based criteria?” *Human Reproduction*, Volume 32, Issue 2, 1 February 2017, Pages 261–264, <https://doi.org/10.1093/humrep/dew287>

⁵⁴ Sydney Parker, “When Missed Periods are a Metabolic Problem,” *The Atlantic*, June 26, 2015, https://www.theatlantic.com/health/archive/2015/06/polycystic-ovary-syndrome-pcos/396116/?gclid=CjwKCAjw8MD7BRArEiwAGZsrBcuVLyJYOjSQvc32pqn7aShYWGfM5Cg0Ek202SPzpXYEop2BJfN0ORoCoUYQA_vD_BwE.

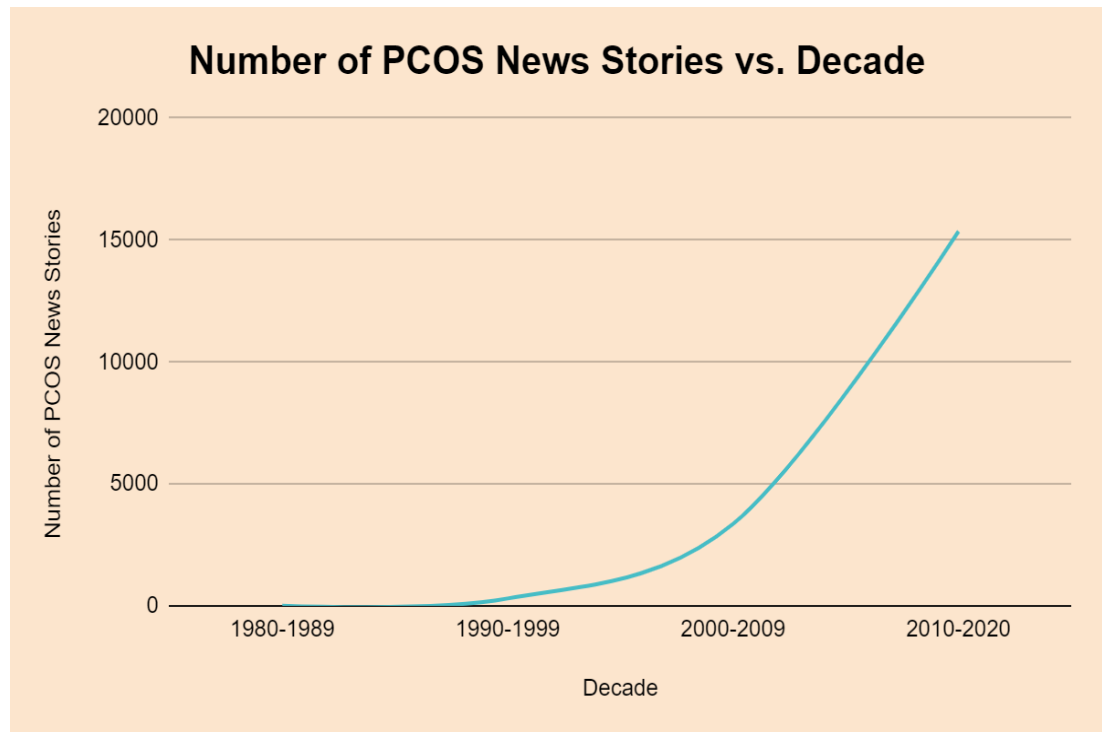


Figure 2. Nexis Uni search for news stories regarding PCOS from 1980-2020.⁵⁵

Although the increased PCOS references in both the medical literature and mainstream news stories are surely welcome news to those who struggle with PCOS, a dearth of news coverage about this common disorder remains, especially when compared to other medical conditions. While PCOS “... affects more women than breast cancer, rheumatoid arthritis, multiple sclerosis, and lupus combined,”⁵⁶ that fact is not reflected in media coverage of the disorder. The number of news stories in the past year on PCOS is dwarfed by other diseases and disorders such as epilepsy and tuberculosis.

⁵⁵ Nexis Uni search terms used: “Stein Leventhal Syndrome,” “Polycystic Ovarian Syndrome” and “Polycystic Ovary Syndrome.”

⁵⁶ Marie McCullough, "Championing the cause of PCOS," *The Philadelphia Inquirer*. October 21, 2018, Sunday, <https://advance-lexis-com.proxy1.library.jhu.edu/api/document?collection=news&id=urn:contentItem:5TJ3-TDW1-DYJT-2207-00000-00&context=1516831>

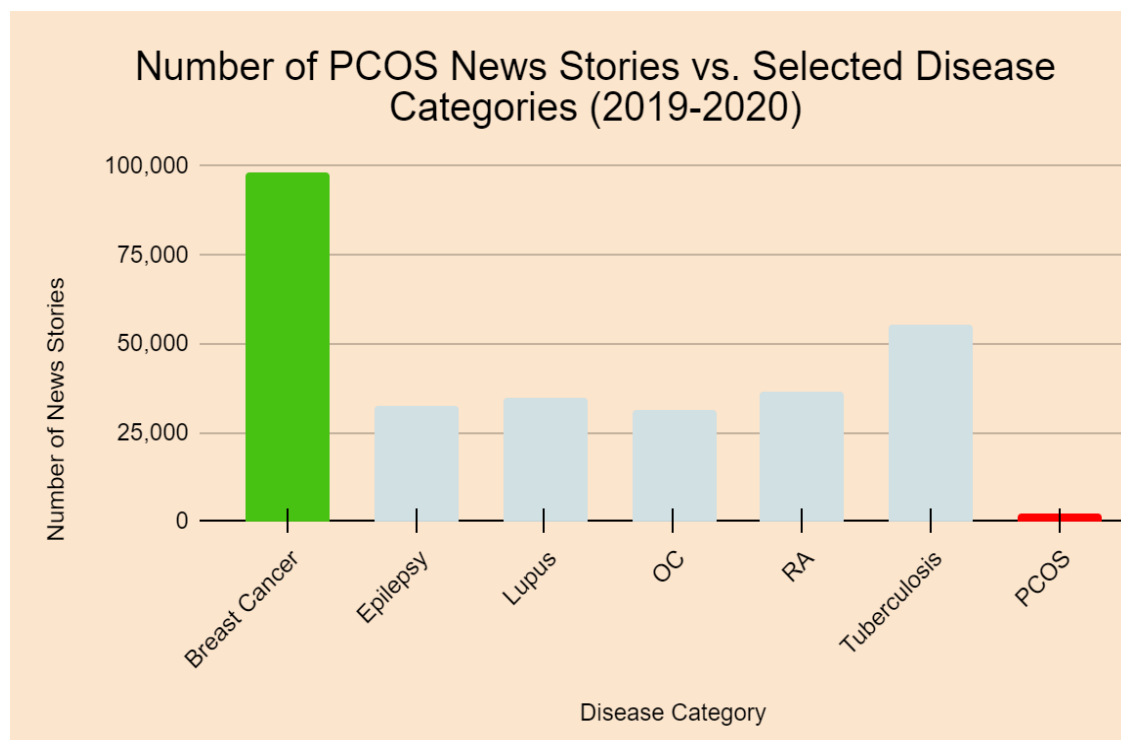


Figure 3. Nexis Uni search for news stories about selected disease categories in 2020.⁵⁷

For those reasons and more, people living with PCOS still do not have quick, ready or helpful answers to manage the symptoms they face and answer the questions they have about this incurable disorder. In the absence of those answers, women with PCOS formed their own Patient Advocacy Organizations (PAOs) to address the questions and experiences related to PCOS.

Forming PAOs has had a long history within the United States. For the purposes of this memorandum, PAOs will be as defined by Susannah L. Rose, *The Journal of Law, Medicine & Ethics*: “PAOs are formally organized nonprofit groups that concern themselves with medical conditions or potential medical conditions and have a mission and take actions that seek to help

⁵⁷ Timeframe for Nexis Uni search is November 22, 2019 to November 21, 2020. Shortened disorder titles OC and RA refer to ovarian cancer and rheumatoid arthritis.

people affected by those medical conditions or to help their families.”⁵⁸ Well-known PAOs include the American Cancer Society (founded in 1913) and National Alliance on Mental Illness (founded in 1979).

PAOs also works to raise public awareness by educating the public about diseases and disorders and lobbying elected officials on the federal, state and local levels changing legislation related to the diseases they represent.”⁵⁹ Another area of critical importance to PAOs is research, including “the design and implementation of studies,”⁶⁰ as well as a key role in establishing resources necessary to support and encourage research.⁶¹ Finally, PAOs have embraced social media “to connect, communicate, fundraise and raise awareness,” as well as “connect with scientists interested in their diseases, and share their stories with individuals in industry or the investment community who may see opportunities that otherwise would not come to their notice.”⁶²

Several PCOS organizations have formed, following that in that tradition, because “PCOS awareness and support organizations receive less than 0.1 percent of the government, corporate, foundation, and community funding that other health conditions receive.”⁶³ Organizations such as Soul Cysters and the Endocrine Society through its Hormone Health Network are supporting the work of building both PCOS awareness and health promotion. Other

⁵⁸ Susannah L. Rose, “Patient Advocacy Organizations: Institutional Conflicts of Interest, Trust, and Trustworthiness,” *The Journal of Law, Medicine & Ethics: A Journal of the American Society of Law, Medicine & Ethics* vol. 41,3 (2013): 680-7. doi:10.1111/jlme.12078

⁵⁹ Ibid.

⁶⁰ Mary Dunkle, (2014), “A 30-Year Retrospective: National Organization for Rare Disorders, the Orphan Drug Act, and the Role of Rare Disease Patient Advocacy Groups,” *Orphan Drugs: Research and Reviews* 4: 19-27. doi: <http://dx.doi.org/10.2147/ODRR.S41070>.
<http://proxy.library.jhu.edu/login?url=https://www.proquest.com/docview/2227425140?accountid=11752>.

⁶¹ Ibid.

⁶² Ibid.

⁶³ Sydney Parker, “When Missed Periods are a Metabolic Problem,” *The Atlantic*, June 26, 2015, https://www.theatlantic.com/health/archive/2015/06/polycystic-ovary-syndrome-pcos/396116/?gclid=CjwKCAjw8MD7BRArEiwAGZsrBcuVLyJYOjSQvc32pq7aShYWGfM5Cg0Ek202SPzpXYEop2BJfN0ORoCoUYQAvD_BwE

groups such as the Women's Health Information, Polycystic Ovarian Syndrome Support Blog and the Hormone Foundation⁶⁴ have formed to fill the breach to more fully understand PCOS for women and girls who are living with the disorder.

Two organizations, however, are targeting PCOS-related issues in the systematic manner described by Susannah Rose's article in *The Journal of Law, Medicine & Ethics*: One organization is the Polycystic Ovarian Syndrome Association, a non-profit organization dedicated to PCOS advocacy by "... providing educational and support services to help people understand what the disorder is and how it can be treated." The Association also provides support for people diagnosed with PCOS to help them overcome the disorder and decrease the impact of its associated health problems.⁶⁵

It is the PCOS Challenge: The National Polycystic Ovary Syndrome Association, however, the self-described leading nonprofit patient support and advocacy organization that has moved beyond promoting health solutions solely by adding political advocacy to promote greater awareness among elected leaders and demand greater research into PCOS. Currently, the organization has taken concrete actions in raising the disorder's profile. In 2017, the organization "built a coalition of over 70 major national and international health organizations and led the first-ever successful legislative advocacy effort in the U.S. Congress to recognize the seriousness of PCOS, the need for further research, improved treatment and care options, and for a cure for PCOS and to designate September as PCOS Awareness Month."⁶⁶ Other measures PCOS Challenge has undertaken include hosting annual lobby days and symposia as well as starting a Twitter handle to bolster its advocacy and awareness efforts on social media.

⁶⁴ Insulite Health, accessed on October 3, 2020, <https://pcos.com/pcos-organizations-and-support-links>.

⁶⁵ PCOS Awareness Association, accessed on October 2, 2020, <https://www.pcosaa.org>.

⁶⁶ PCOS Challenge: The National Polycystic Ovary Syndrome Association, accessed on October 4, 2020, <https://pcoschallenge.org/pcos-advocacy-day/public-policy>.

PCOS champions are being developed since the playing field is relatively new in terms of advocacy. Currently, PCOS Challenge’s main legislative champions are Representative David Scott (D-GA-13) and Senators Elizabeth Warren (D-MA) and David Perdue (R-GA). They are the lead sponsors for H.Res.495 and S.Res.336 which “recognize(s) the seriousness of polycystic ovary syndrome (PCOS), the need for further research, improved treatment and care options, and for a cure for PCOS.”⁶⁷

Representative Scott, along with Representative Debbie Wasserman Schultz, issued a “Dear Colleague” letter urging their colleagues’ support to insert report language regarding PCOS in the 2021 Labor-HHS Appropriations bill. The letter urges Subcommittee Chairwoman Representative Rosa DeLauro and Ranking Member Representative Tom Cole to encourage “interagency research” of PCOS at NIH⁶⁸ in the appropriations bill. This effort proved successful. The report language in H. Rept. 116-450 recommends that the National Institute of Child Health and Human Development (NICHD) partner with the National Heart, Lung, and Blood Institute (NHLBI) “... to promote research in PCOS, particularly with a focus on comorbidities” and “encourages NHLBI to report on research that has been conducted on PCOS and its impact on cardiovascular health to date in the fiscal year 2022 Congressional Justification.”⁶⁹

⁶⁷ <https://pcoschallenge.org/prioritize-pcos>, accessed on October 4, 2020.

⁶⁸ Representative Debbie Wasserman Schultz, “Dear Colleague” letter: “Support Polycystic Ovary Syndrome (PCOS) Research at NIH in FY21 Deadline: COB March 6, 2020,” <http://dearcolleague.us/2020/02/polycystic-ovary-syndrome-pcos-research-funding-at-nih-sign-fy-2021-appropriations-letter/>.

⁶⁹ H. Rept. 116-450, Departments Of Labor, Health And Human Services, And Education, And Related Agencies Appropriations Bill, 2021, accessed on October 18, 2020, <https://www.congress.gov/congressional-report/116th-congress/house-report/450/1?q=%7B%22search%22%3A%5B%22labor+hhs+appropriations+2021%22%5D%7D>.

IV. Policy Proposal

The goal of this policy proposal is to preserve access to needed medicines for all women and girls with PCOS, direct research to unlock answers about PCOS's origins and increase awareness among women, girls and health care providers in the United States by 20 percent in five years, by addressing the disorder's knowledge and awareness gaps. Because the disorder is complex and its symptoms are varied (therefore affecting women and girls differently), the solution to advance understanding must be multi-pronged and comprehensive, while keeping some of its more dangerous symptoms at bay.

The proposed remedy to these concerns is to use this policy proposal as the framework of a bill, ideally to be cosponsored with Representative David Scott. This proposal would build upon the foundational work to advance public awareness (and awareness among Members of Congress) about PCOS that was accomplished in the 116th Congress. This legislative proposal would build on both the PCOS awareness-building goals within H.Res.495 and S.Res.336 and encouragement of "interagency research" of PCOS at NIH as directed in H. Rept. 116-450 to advance a more robust and holistic approach to addressing PCOS and finding answers to the disorder. Implementing this policy would codify the right to birth control, increase research funding and the number of PCOS researchers by 20 percent by 2030 and conduct a public education to raise public awareness about the disorder.

Specifically, this legislative proposal would protect the medicines women and girls depend on now while expanding research, strengthening the pipeline for more PCOS researchers and promoting public education for the future. It mirrors both the *Uterine Fibroid Research and Education Act* introduced by Senator Kamala Harris and Representative Yvette Clarke⁷⁰ and the

⁷⁰ S. 4397, "The Uterine Fibroid Research and Education Act of 2020," <https://www.congress.gov/bill/116th-congress/senate-bill/4397/text?q=%7B%22search%22%3A%5B%22uterine+fibroids%22%5D%7D&r=2&s=3>.

Maternal CARE Act introduced by Senator Kamala Harris and Representative Alma Adams⁷¹ and pairs it with additional elements to offer a comprehensive legislative solution that can begin to answer long-standing questions regarding PCOS and to find a cure.

The proposed legislation would first seek to ensure women and girls have continued to access oral contraceptives, a medicine that has traditionally helped people manage the disorder and keep its more serious symptoms and disease developments at bay. The Affordable Care Act (ACA) required most health insurance companies to cover birth control without copay in their plans, making it more affordable.⁷² But the *Little Sisters of the Poor v. Pennsylvania* ruling, along with other regulatory attacks on contraception, threatens this access, adding an economic burden atop the medical burden. Indeed, “... co-pays for birth control pills typically range between \$15 and \$50 per month. That adds up to over \$600 per year.”⁷³

The proposal can help protect access to this medicine by adopting H.R.7517, the *Protect Access to Birth Control Act* sponsored by Representative Diana DeGette. This language would maintain access to this needed medication by nullifying interim final rules issued by the Departments of Labor, Treasury, and Health and Human Services (HHS) “... that allow employers with religious or moral objections to be exempt from the requirement that their health insurance plans cover contraceptive services without cost-sharing.”⁷⁴

⁷¹ S. 1600, “The Maternal CARE Act,” <https://www.congress.gov/bill/116th-congress/senate-bill/1600/text?q=%7B%22search%22%3A%5B%22maternal+health+care%22%5D%7D&r=3&s=1>

⁷² <https://www.plannedparenthoodaction.org/issues/birth-control/facts-birth-control-coverage>, accessed on October 9, 2020.

⁷³ Ibid.

⁷⁴ H.R.7517, “The Protect Access to Birth Control Act,” accessed on October 19, 2020, <https://www.congress.gov/bill/116th-congress/house-bill/7517/text?q=%7B%22search%22%3A%5B%22birth+control+access%22%5D%7D&r=1&s=2>.

Using oral contraceptives to manage and mitigate the effects of PCOS, while a routine and often critical tool used to control the disorder, is not the complete answer. Although women and girls with PCOS often present with similar symptoms, they neither share the same symptoms nor severity of those symptoms, which can vary greatly as well. Because of these variances, oral contraceptives may not always be the medically appropriate treatment for every woman or girl with PCOS. In addition, those who wish to conceive will not cease to have PCOS when oral contraceptives are discontinued, or when post-menopausal women decide to forgo taking the medicine. To address those instances, newer and more effective solutions for care and treatment are needed that can only be discovered and developed by further research.

While NIH spends nearly \$42 billion in medical research annually,⁷⁵ less than 0.1 percent of that amount is targeted toward PCOS research.⁷⁶ To begin to remedy that disparity, the proposal's second purpose would expand the scant PCOS research dollars by providing \$50 million annually for FY22-FY27 to NIH to expand research on PCOS, with a focus on expanding interagency research as recommended in H. Rept. 116-450 and PCOS research in other NIH Institute Centers in addition to NICHD.

Currently, more than "... 70 percent of NIH's investment in PCOS research has focused on symptoms and comorbidities that impact women's reproductive health,⁷⁷ mostly through NICHD.⁷⁸ This legislative proposal would provide funding to NHLBI as well as the National Institutes of Diabetes and Digestive and Kidney Diseases (NIDDK), to promote balance and

⁷⁵ National Institutes of Health, accessed on November 22, 2020, <https://www.nih.gov/about-nih/what-we-do/budget#:~:text=The%20NIH%20invests%20about%20%2441.7,research%20for%20the%20American%20people>.

⁷⁶ Angela Grassi, "Why Is PCOS Ignored?" *U.S. News & World Report*, August 30, 2017, <https://health.usnews.com/health-care/for-better/articles/2017-08-30/why-is-pcos-ignored>.

⁷⁷ Representative Debbie Wasserman Schultz, "Dear Colleague" letter: "Support Polycystic Ovary Syndrome (PCOS) Research at NIH in FY21 Deadline: COB March 6, 2020." <http://dearcolleague.us/2020/02/polycystic-ovary-syndrome-pcos-research-funding-at-nih-sign-fy-2021-appropriations-letter/>.

⁷⁸ Soumia Brakta, Daria Lizneva, Kateryna Mykhalchenko, et al., "Perspectives on Polycystic Ovary Syndrome: Is Polycystic Ovary Syndrome Research Underfunded?" *The Journal of Clinical Endocrinology & Metabolism*, Volume 102, Issue 12, 1 December 2017, Pages 4421–4427, <https://doi.org/10.1210/jc.2017-01415>.

collaboration between reproductive and metabolic research. Funding NHLBI and NIDDK in addition to NHCHD would focus on examining the disorder’s long-term consequences in women, including the development of type 2 diabetes, cardiovascular diseases and hormone-dependent cancers.⁷⁹

This proposal also seeks to open additional avenues of PCOS research. Similar to the Harris-Clarke legislation, this proposal would include PCOS as a condition category in the Centers for Medicare & Medicaid Services (CMS) Chronic Conditions Data Warehouse (CCW) “... a research database designed to make Medicare, Medicaid, Assessments, and Part D Prescription Drug Event data more readily available to support research designed to improve the quality of care and reduce costs and utilization.”⁸⁰ Adding PCOS to the list of 40 “chronic health, mental health, substance abuse, and potentially disabling condition categories”⁸¹ in addition to the chronic diseases it chronicles would “support health policy analysis,”⁸² another stated CCW goal.

In addition, the proposal also would improve and expand research by adding PCOS as a research program in the Congressionally Directed Medical Research Programs (CDMRP), a Department of Defense (DOD) program that awards and manages competitive research grants. Started in 1992 when Congress appropriated funds to DOD to fund breast cancer research, CDMRP “... receives congressional appropriations explicitly for biomedical research in specific, congressionally identified health matters. As such, it is not part of the President’s budget request for the DOD.”⁸³

⁷⁹ Renato Pasquali, et al., “PCOS Forum: research in polycystic ovary syndrome today and tomorrow,” *Clinical Endocrinology*, 74(4), 424–433. <https://doi.org/10.1111/j.1365-2265.2010.03956.x>

⁸⁰ <https://www2.ccwdata.org/web/guest>, accessed on October 12, 2020.

⁸¹ Ibid.

⁸² Ibid.

⁸³ Bryce H. P. Mendez, “Congressionally Directed Medical Research Programs Funding for FY2020,” Congressional Research Service, accessed on October 14, 2020, <https://crsreports.congress.gov/product/pdf/IF/IF10349>.

The U.S. Army Medical Research and Development Command is responsible for administering CDMRP. These research grants also are ideal for furthering the knowledge about the disorder because of its stated goal to “... of advancing paradigm-shifting research, solutions that will lead to cures or improvements in patient care, or breakthrough technologies and resources for clinical benefit”⁸⁴ as well as “... target[in] critical research gaps”⁸⁵—exactly what is required to better understand PCOS and find a cure. Stakeholder and vision setting meetings allow for surveying the current research landscape, identifying research opportunities and developing recommended investment strategies to fill those gaps.⁸⁶ This proposal seeks the inclusion of PCOS as a category with a funding total of \$10 million in FY2022.⁸⁷

Next, the proposal would direct NIH to prioritize PCOS researcher support through the New and Early Stage Investigator Awards to bridge the researcher gap and bolster the number of researchers addressing PCOS. This would strengthen the researcher pipeline by encouraging experienced biomedical and public health researchers to study PCOS and collaborate with patients to identify more effective treatments and a possible cure for PCOS. Including support for additional PCOS researchers would align with NIH’S goal of “supporting and training world-class researchers”⁸⁸ and the initiative’s goals “to address longstanding challenges faced by researchers trying to embark upon and sustain independent research careers, and to take steps to promote the growth, stability and diversity of the biomedical research workforce.”⁸⁹

⁸⁴ 2019 Annual Report, “Congressionally Directed Medical Research Programs, US Army Medical Research and Development Command,” September 30, 2019, <https://cdmrp.army.mil/pubs/annreports/2019annrep/2019annreport.pdf>.

⁸⁵ Ibid, p.7.

⁸⁶ Ibid, p.9.

⁸⁷ Ibid, p5.

⁸⁸ “Impact of NIH Funding,” <https://www.nih.gov/about-nih/what-we-do/impact-nih-research/our-knowledge>

⁸⁹ “Next Generation Researchers Initiative,” accessed on October 18, 2020, <https://grants.nih.gov/ngri.htm>.

Finally, this legislative proposal would deepen the knowledge about PCOS among women and girls as well as health care providers through education efforts. It would direct the CDC, the Health Resources Service Administration (HRSA) and the Agency for Healthcare Research and Quality (AHRQ) to disseminate information about PCOS. The CDC would disseminate information to the public, while HRSA and AHRQ would disseminate information to health care providers so that they are informed about current information on PCOS, how to diagnose it and the current range of available treatment and disorder management options.

V. Policy Analysis

This policy proposal advances a more comprehensive PCOS policy solution legislatively via a bill cosponsored with Representative David Scott to address PCOS in a multifaceted way. This legislative proposal would build on both the PCOS awareness-building goals within H.Res.495 and S.Res.336 and encouragement of “interagency research” of PCOS at NIH as directed in H. Rept. 116-450 to advance a more robust and holistic approach to addressing PCOS and finding answers to the disorder. Implementing this policy would codify the right to birth control, establish PCOS-specific research, add more PCOS researchers in 10 years and raise public awareness of disorder by 20 percent among both healthcare providers and women and girls.

The ACA, among its many benefits, made oral contraceptives affordable to more women. A graph presented by the Kaiser Family Foundation (Figure 4) shows a steep decline in the percentage of women 15-44 reporting out-of-pocket spending for hormonal contraceptives, which represents a great deal of progress made in a short amount of time.

But the ACA was not a panacea. While its provisions eliminated most of the out-of-pocket costs for contraception for most insured women, some are still paying them.⁹⁰ A recent ScienceDirect study showed that “... 10 percent of oral contraceptive users in large employer

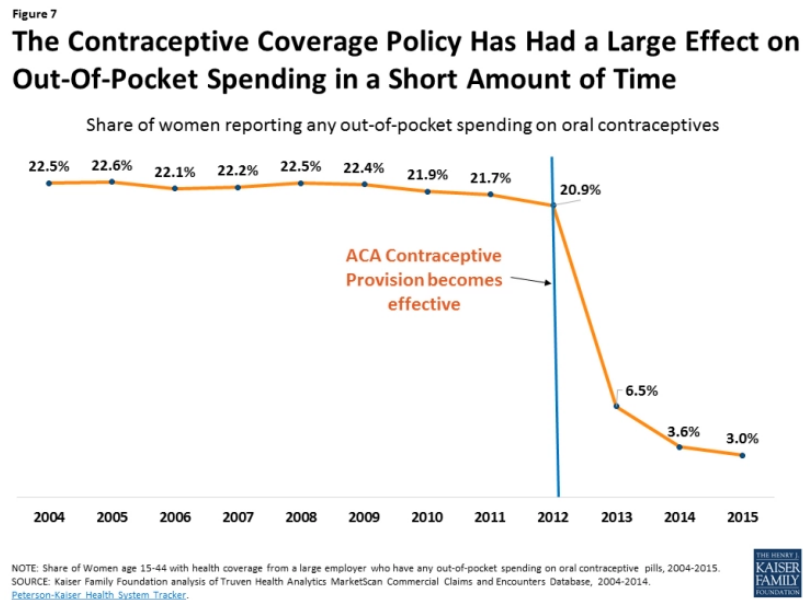


Figure 4. The effect of contraceptive coverage on out-of-pocket spending.⁹¹

plans still had out-of-pocket costs in 2018.” It was also noted that generic versions of that contraception do not exist.⁹²

⁹⁰ Brittnei Frederiksen, Matthew Rae and Alina Salganicoff, “Out-of-pocket spending for oral contraceptives among women with private insurance coverage after the Affordable Care Act,” *Contraception: X*, Volume 2, 2020, 100036, ISSN 2590-1516, accessed on October 31, 2020, <https://doi.org/10.1016/j.conx.2020.100036>. (<http://www.sciencedirect.com/science/article/pii/S2590151620300198>).

⁹¹ Kaiser Family Foundation, “The Contraceptive Coverage Policy Has Had a Large Effect on Out-Of-Pocket Spending in a Short Amount of Time,” accessed on October 31, 2020, <https://www.kff.org/womens-health-policy/issue-brief/ten-ways-that-the-house-american-health-care-act-could-affect-women/>.

⁹² Ibid.

The progress on the affordability aspect as well as the access to oral contraceptives is threatened by the Supreme Court case. This proposal would seek to expressly enshrine this right to access into law. Doing so, however, will draw the ire—and legal challenges—from some anti-abortion and other conservative advocacy groups, although some splits among the groups exist regarding oral contraceptive use.⁹³ Another drawback to this portion of the policy proposal is that while oral contraceptives are commonly used to manage PCOS symptoms, not every girl or woman is prescribed it as a treatment option. Also, although this provision would be the most controversial aspect of the proposal, focusing on the oral contraceptive aspect is a limitation. While protecting the most common way to manage the disorder is crucial, it neither deepens the knowledge about PCOS nor does it help find a cure. “The current standard of care is generally aimed at relieving the patient’s individual symptoms. This means, for instance, prescribing treatments for acne and diabetes, or oral contraceptives to regulate the menstrual cycle.”⁹⁴ Women and girls with PCOS need other options to more precisely pinpoint their care. Those options do not yet exist.

That is why the second part of the policy proposal, supporting research and encouraging more PCOS researchers, is of great importance. Increased and more focused research will bring greater attention to the disorder, as well as more effective integration between the reproductive and metabolic aspects of PCOS. Including the disorder on the list of eligible conditions or treatment for CDMRP medical research grants for the first time will enhance its importance in the research community as well as deepen the knowledge about the disorder. Similarly, including PCOS as a disease in the CCW will help in achieving this goal as well, since it also serves as a

⁹³ Piper Hudspeth Blackburn, HyoJung Kim and Mark Satter, “Is Access to Birth Control Caught in the Crosshairs of the 2020 Abortion Debate?” Medill News Service, February 21, 2020, <https://dc.medill.northwestern.edu/blog/author/piperhyojungmark/#sthash.u5jTvmYi.dpbs>.

⁹⁴ *research, The Bayer Scientific Magazine*, <https://www.research.bayer.com/en/polycystic-ovary-syndrome-therapy.aspx>. Last updated on October 9, 2017.

data source for the Healthy People 2030 initiative that seeks to improve health outcomes nationwide by addressing specific public health priorities.⁹⁵

Joining with PCOS resolutions cosponsors Representative Tim Ryan (as a member of the DOD appropriations subcommittee) and Representatives Mark Pocan and Bonnie Watson Coleman (as members of the Labor-HHS appropriations subcommittee) can help move these efforts forward. While the funds appropriated may be insufficient to the sheer dearth of knowledge about PCOS immediately, this section of the proposal may affix PCOS more firmly on the research map, representing an evolution of PCOS as a legitimate health concern worthy of more serious exploration.

The policy proposal's third component directs the NIH to create programs, including grants, to incentivize a greater number of medical researchers to address the dearth of PCOS specialists and researchers. Dr. Andrea Dunaif, M.D., the chair of endocrinology at Mount Sinai School of Medicine, explains this succinctly: "The lack of funding for PCOS research also discourages some young scientists from entering this field" and says "... a dearth of research money can steer potential scientists away from taking a chance on grant writing."⁹⁶

Dr. Ricardo Azziz, chief officer of academic health and hospital affairs at the State University of New York says, "... sometimes good researchers end up leaving the field" and "... with fewer competitive researchers come fewer breakthrough studies."⁹⁷ For example, the number of PCOS research grant applications dropped 42 percent from 2006 to 2015, according to Dr.

⁹⁵ U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, Healthy People 2030; <https://www.healthypeople.gov/2020/About-Healthy-People/Development-Healthy-People-2030>

⁹⁶ Mary Claire Lagroue, "Why Is PCOS Still So Hard for Doctors to Understand? Advocates and researchers are pushing for awareness," *Self*, September 12, 2019, <https://www.self.com/story/pcos-doctors-medical-mystery>.

⁹⁷ Ibid.

Azziz's research.⁹⁸ But while encouraging more PCOS researchers is a positive goal, no established standards of training and metrics yet exist to measure if the requisite number of researchers are being trained and supplied. The legislation also cannot guarantee that a person who begins or continues a career as a PCOS researcher will continue with that research area over the long term.

The last part of the policy proposal directs HHS to design and implement a public education campaign to reach both women and girls, as well as healthcare providers and increase their knowledge about PCOS and its symptoms. According to Monash University's Helena Teede, a major part of the problem to date with PCOS has been "... the absence of guidelines with education and support for healthcare providers."⁹⁹ To help bridge this gap, the proposal will fund a public education campaign aimed at raising awareness to increase by 20 percent the number of women and girls seeking a PCOS diagnosis, and reaching 20 percent of healthcare providers so that they are more familiar with the disorder, and its symptoms—and sometimes its lack of definite symptoms. The drawback is that such a campaign will almost certainly compete with other public health campaigns with the same goals. Driving that message in such a crowded media environment will be a challenging undertaking and one that will take time for target audiences to receive and absorb.

The overall goal of the policy proposal is to decrease the number of undiagnosed PCOS cases due to the lack of knowledge about the disorder. The legislation will establish PCOS policy on a federal level, and by so doing, add long-missing grounding and permanence to PCOS policy

⁹⁸ Soumia Brakta, Daria Lizneva, Kateryna Mykhalchenko, et al., "Perspectives on Polycystic Ovary Syndrome: Is Polycystic Ovary Syndrome Research Underfunded?" *The Journal of Clinical Endocrinology & Metabolism*, Volume 102, Issue 12, 1 December 2017, Pages 4421–4427, <https://doi.org/10.1210/jc.2017-01415>.

⁹⁹ Rebeka Powell, "Monash University's Helena Teede, a major part of the problem to date with PCOS," Australian Broadcasting Corporation, April 27, 2018, <https://www.abc.net.au/news/2018-04-28/polycystic-ovary-syndrome-women-on-life-with-pcos/9607494?nw=0>.

since it would require Congressional approval to be changed once passed. At the same time, the choice to introduce the policy through legislation is time-consuming and holds no guarantees of its passage. However, the benefit of this policy proposal as enacted legislation would be to decrease the more than \$4 billion annually spent on PCOS-related health costs. It would also decrease the occurrence and attendant financial costs of infertility, maternal and infant health issues (such as preeclampsia and low birth weight babies), chronic diseases and depression.

Overall, the components of the policy proposal have the potential to greatly further the knowledge about PCOS among women and girls, healthcare providers and the research community, not simply because it has not been a public health priority given its prevalence, but because PCOS itself is unknown by so many, including those who have the disorder but are unaware of it. Increasing awareness by 20 percent of women and girls as well as healthcare providers would be a great leap forward to make progress on PCOS.

VI. Political Analysis

Polycystic Ovary Syndrome, while a relatively unknown health issue, is not a controversial one. Since the elements that form this proposal have significant points of social acceptability, the time to advance this policy is now.

The most controversial part of this bill is protecting access to oral contraceptives, which is an important medicine to help manage (and in some instances, counteract) the disorder's most serious symptoms. Although passing an oral contraceptive/birth control bill with the current composition of the Senate would be difficult at best, birth control and oral contraceptives are popular with the American public. In fact, a favorable view of birth control and oral contraceptives has remained durable over the years.

Gallup first polled Americans about birth control in 1937: “Sixty-one percent of Americans in this poll said they supported the birth control movement, while 26 percent said no, and 13 percent gave no answer.”¹⁰⁰ Oral contraceptives were introduced in the United States in 1950, and with it, increased chances for greater freedom and bodily autonomy.”¹⁰¹ In 2010, 50 years after its introduction, 75 percent of American women indicated they had used birth control pills, according to a CBS poll.”¹⁰² And in 2015, when Gallup polled about the moral acceptability of birth control nearly 90 percent of the country said it was.¹⁰³

Americans also hold positive views about the role of research and health information—a major facet of this proposal—to learn about and prevent disease and disorders. According to research conducted by the Pew Research Center: Science and Society, “... many Americans pay attention to health information in the media about ways people can protect themselves from the risk of serious disease.”¹⁰⁴ “Most members of the public (55 percent) say they hear or read news stories about the ways people can protect themselves from the risk of serious diseases every day (16 percent) or a few times a week (40 percent).”¹⁰⁵

Women’s health issues have garnered more media attention in recent years. For example, maternal mortality rates have begun to be discussed more thoroughly. Since 2007, the United States failed to publish a national maternal mortality rate;¹⁰⁶ publication of these mortality rates

¹⁰⁰ “Public Attitudes about Birth Control,” Roper Center, Cornell University, accessed on November 15, 2020, <https://ropercenter.cornell.edu/public-attitudes-about-birth-control>.

¹⁰¹ Pamela Verma Liao and Janet Dollin, “Half a century of the oral contraceptive pill: historical review and view to the future,” *Canadian family physician Medecin de famille canadien* vol. 58,12 (2012): e757-60, accessed on November 11, 2020, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3520685>.

¹⁰² Ibid.

¹⁰³ Ibid.

¹⁰⁴ Pew Research Center: Science and Society, accessed on November 15, 2020, <https://www.pewresearch.org/science/2017/02/02/americans-views-about-public-health-and-health-studies-in-the-news/>.

¹⁰⁵ Ibid.

¹⁰⁶ Julia Belluz, “We finally have a new US maternal mortality estimate. It’s still terrible,” *Vox*, January 30, 2020, <https://www.vox.com/2020/1/30/21113782/pregnancy-deaths-us-maternal-mortality-rate>.

has only recently been restarted. According to the CDC, “... about 700 women die each year in the United States as a result of pregnancy or delivery complications.”¹⁰⁷

Similarly, issues of Black maternal mortality have started to attract media attention as well. The topic has been examined in mainstream media and platforms from the *New York Times* to *Glamour* to NBC News. Indeed, a Nexis Uni search of “Black maternal mortality” found only 15 news stories in 2017, compared with 166 in 2020—a small number of stories, but an obvious uptick nonetheless. Black maternal health mortality issues were also raised by Democratic Senators during the confirmation hearings for now-Justice Amy Coney Barrett.¹⁰⁸

Given the convergence of issues, it can be argued that PCOS’ policy time has come. The disorder’s status as an emerging health policy issue—paired with the fact that this “new” issue has affected so many women and girls across the country for decades—can make this policy proposal a favorable one to support. Pursuing this policy can show that Congress can be proactive about an issue that affects millions of people. Also, that the American public seems to embrace the importance of receiving health information bodes well for the acceptance of factual, evidence-based, health messages about PCOS, how to work with health care professionals to identify the disorder and how to find a plan to manage its symptoms.

The policy actors, for now, are broad but not deep. When examining stakeholders around this disorder, PCOS Challenge emerges as the most engaged actor. This policy proposal would likely garner support from other stakeholders including women’s groups, women’s health

¹⁰⁷ U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; “Maternal Mortality,” accessed on November 11, 2020, <https://www.cdc.gov/reproductivehealth/maternal-mortality/index.html>.

¹⁰⁸ Biba Adams, “Senate Democrats highlight Black maternal health care stories amid confirmation of Amy Coney Barrett,” *The Grio*, October 20, 2020, <https://thegrio.com/2020/10/20/senators-obamacare-barrett-court>.

advocates and organizations such as the Endocrine Society and its Hormone Health Network, as well as infertility groups.

The proposal does hold some risk for attracting either tepid or no support from infertility groups, however, if they perceive that a balancing of potential PCOS research dollars (that is, harmonizing research between metabolic and hormonal research instead of maintaining the lion's share of the already meager research dollars into the reproductive aspects of PCOS) threatens advancement on their core issues. Despite that potential roadblock, most stakeholders would agree that PCOS must be addressed. Based on the work of PCOS activists, your Congressional colleagues would agree with that assessment as well and would likely be amenable to the remedies found in this proposal.

To be clear, PCOS references in the House and Senate have been relatively recent—and rare. The earliest Congressional mention of PCOS found on Congress.gov is a reference in a letter to then-Representative Randy “Duke” Cunningham to support the Biomedical Revitalization Resolution of 2000 to support an increase in NIH funding. Other instances of PCOS mentions since that time were limited to references about either diabetes or birth control, but not as a single issue deserving attention, study or legislative remedy.

For example, PCOS garnered a one-sentence mention in prepared remarks during a 2011 Senate hearing on the Labor-HHS bill to support NIH funding for the National Primate Research Centers, whose mission is described as using “scientific discovery and nonhuman primate models to accelerate progress in understanding human diseases.” It reads, “Researchers and physicians are getting closer to a novel diagnostic test for polycystic ovary syndrome (PCOS), which has

staggering adverse physiological, psychological, and financial consequences for women's reproductive health.”¹⁰⁹

Similarly, another one-time mention of PCOS was during a February 7, 2012, colloquy by then-Senator Barbara Boxer and other Senators including then-Senator Barbara Mikulski and Senator Patty Murray. Senator Boxer said that Senator Kirsten Gillibrand shared with her the story of the Georgetown University law student’s loss of her ovary (the news article is referenced on page eight of this memorandum) because she did not have insurance coverage for contraceptives, and could not afford to pay for the medicine herself. That was the only reference of PCOS during the entire colloquy.

The relative Congressional silence about PCOS changed when Representative Scott introduced H.Res.495 to recognize PCOS and support the designation of September 2017 as "PCOS Awareness Month" in the 115th Congress. This legislation served as the springboard to capture more attention to the disorder. PCOS was also directly referenced H.R.1897, a maternal mortality bill introduced by Representative Robin Kelly. These increased instances of awareness and references have potentially provided the space to move your policy proposal forward.

Although awareness about PCOS among House members is only now beginning to increase, its feasibility to win Congressional approval has an excellent prognosis. You have an opportunity to position PCOS as an issue for the incoming CBC Chair, since a new chair will be voted on by CBC members in the 117th Congress. Advancing this proposal can also help address the serious health gaps women face generally and African American women face in particular.

¹⁰⁹ S.Hrg. 112-337 — Departments Of Labor, Health And Human Services, And Education, And Related Agencies Appropriations For Fiscal Year 2012, 112th Congress (2011-2012), accessed on November 14, 2020, <https://www.congress.gov/event/112th-congress/senate-event/LC1726/text?q=%7B%22search%22%3A%5B%22%5C%22polycystic+ovary+syndrome%5C%22%22%5D%7D&s=6&r=70>.

Separately, you can advance the proposal through your roles in the Black Maternal Health Caucus and Women's Caucus. Bringing this policy proposal forward in the Black Maternal Health Caucus especially holds promise. Cofounded by Reps. Alma Adams and Lauren Underwood in 2019, the Caucus has quickly become a bi-partisan one of more than 100 members as of January 2020. Your policy proposal can help draw attention to the Caucus' work by making real progress on PCOS, shedding light on understanding the disorder as well as increasing awareness so that women and girls can detect PCOS, understand its effects and take steps to guard their health. Finally, the proposal would represent another example of your policy insight and action as you consider your next leadership role.

VII. Recommendation

Based on the analyses presented in this memorandum, I recommend that you proceed with the policy proposal. It would represent a significant improvement in women's health outcomes.

Despite the likely Senate opposition to oral contraceptives, the outlined proposal would signal that all medicines that can improve women's health will be protected, which is both a health care issue and a women's equality issue.

Just as importantly, the proposal would help make progress in an underserved aspect of women's health by increasing much-needed research dollars to the disorder, as well as ensuring that research is harmonized by examining all aspects of this multifaceted disorder. Progress in better understanding the disorder could lead to breakthroughs that may prevent the onset of chronic diseases such as diabetes and cardiovascular disease which drive up the nation's health care costs. Solving PCOS can also help curb depression and its attendant costs as well.

On page two of this memorandum, VCU's Dr. John Nestler noted that researchers are on the cusp of understanding the disorder's full impact. It is time to give them the resources and support required to do so. Funding research and ensuring that the research is appropriately focused is of utmost concern. Plainly stated, research dollars should be on par with the number of women and girls the disorder affects, and that number is in the millions. (Especially so, since diseases affecting women have historically been underfunded.) With this proposal, we can begin to give the doctors, specialists and researchers the crucial support they need to examine the underlying issues about PCOS that they do not yet understand. This proposal also provides an opportunity to balance the reproductive and metabolic aspects of PCOS research without favoring one aspect of the disorder over the other.

Similarly, attracting and retaining researchers is a long-term goal that must begin now. This proposal can help in that regard. Because real or perceived PCOS funding reductions can also contribute to a lack of PCOS researchers, more investment in PCOS can go far in attracting talented research professionals to find answers to this disorder. Increasing the number of PCOS researchers, certainly by the centennial of this disorder's discovery in 2035, is a worthy goal that this policy proposal can help facilitate.

Finally, the proposal's call to craft a solid public education campaign to inform the public and health care professionals about PCOS is a welcome and much-needed step to promote greater awareness about PCOS and how best to tailor treatments to meet the unique needs of each person's symptoms. It is time to give voice to this silent disorder so women and girls are educated about PCOS and armed with facts to make important decisions about their health and treatment options. Health providers and health practitioners also need information about PCOS to bridge their knowledge gaps so they can better advise their patients and provide them with the care they need and deserve.

The work done by other Members of Congress to raise awareness about PCOS is a good and necessary first step. This policy proposal charts a blueprint to take the next steps toward finding answers to better understand PCOS and its origins, providing improved treatments—and eventually, finding a cure.

Curriculum Vitae

Erica Nash-Thomas, originally from Petersburg, Virginia, has a background in strategic and leadership communications, public affairs and internal communications gained from her work in the United States House of Representatives, the United States Senate, for the Governor of Maryland and for associations such as AARP and the National Education Association. She covered a range of issues including economic development and housing issues as part of her issue portfolio for Senator Charles S. Robb, where she was acknowledged by then-Treasury Secretary Lawrence H. Summers for work on the New Markets Initiative, a program designed to spur business investment to revitalize communities around the country.

Nash-Thomas began her speechwriting career crafting speeches for Governor Parris N. Glendening covering health policy, the environment and transportation, and wrote remarks to welcome South African President Nelson Mandela at the University of Maryland at College Park, where Governor Glendening previously served as a professor. As a consultant to the American Alliance of Museums, she developed speeches delivered before international audiences in Argentina and South Korea. Additionally, Nash-Thomas has participated on panels and delivered presentations regarding the speechwriting process and was awarded the International Academy of Digital Arts and Sciences' Webby Award: Official Honoree, Personal Blog/Website category for her personal blog on speeches and speechwriting.

Currently, Nash-Thomas is a Speechwriter/Strategist carrying out the responsibilities of the Chief Speechwriter with the Federal Motor Carrier Safety Administration (FMCSA) at the U.S. Department of Transportation, where she lends her leadership communications expertise to FMCSA's senior leadership.

Among her memberships, Nash-Thomas is a Patient Advisory Board Member for PCOS Challenge: The National Polycystic Ovary Syndrome Association; Secretary, Board of Directors for the Pearl Elegance Foundation; a member of the Professional Speechwriters Association and Washington Speechwriters Roundtable; a member of Alpha Kappa Alpha Sorority, Inc. and a member of the Wives of the Beaux-Twenty Debutante Alumnae Association based in Petersburg, Virginia.

EDUCATION

John Hopkins University, Krieger School of Arts and Sciences, Advanced Academic Programs.

Candidate, Master of Arts in Public Management

- Capstone: “Giving Voice to a Silent Disorder: A Policy Proposal to Address Polycystic Ovary Syndrome”
 - Capstone Advisor: Professor Paul Weinstein
- Courses:
 - *Politics, Culture and Security in India*. Areas visited: New Delhi, Gurgaon, Amritsar and Agra. Lectures, tours and visits (Supreme Court, High Commissioner of Pakistan to India, think tanks) sponsored by the Johns Hopkins University Center for Advanced Governmental Studies.
 - Public Policy and the Policy Process
 - Fundamentals of Quantitative Methods
 - Economics for Public Decision-Making
 - Fundamentals of Nonprofits and Nonprofit Management
 - Proseminar: Essentials of Public & Private Management
 - Strategic Communication Program Management
 - Leadership and Organizational Behavior
 - Negotiating as a Leadership Skill

The University of Maryland at College Park.

Bachelor of Arts in Journalism; minor in Government and Politics

PROFESSIONAL EXPERIENCE

The Yes& Agency, Alexandria, VA

Speechwriter/Strategist

Execute responsibilities of Chief Speechwriter on behalf of the U.S. Department of Transportation/Federal Motor Carrier Safety Administration (DOT/FMCSA) executive leadership. Develop up to 19 speeches, fact sheets, blog posts and presentations per month for principals and other senior leaders. Make recommendations for stakeholder engagement plans. Provide [thought leadership ideation](#). Leverage speeches and remarks into social media content and collateral materials. Co-chair Yes& Agency's Diversity and Inclusion committee. Bolster Yes& Agency's new business efforts. Mentor junior staff.

- Earned "exceptional" CPARS performance rating for quality based on top performance and exemplary client service.
- Develop key messages and content regarding FMCSA's assistive technologies policy, one of the agency's key priorities.

Speechwriter/Editor (Consultant), Bowie, MD

Provided executive communications, media relations, press outreach and editing services for clients and on individual projects. Developed leadership communications plans and craft speeches. Lead press outreach and leadership participation in special events. Prepared clients for media interviews. Leverage remarks into social media content. Direct, review and draft supporting collateral, including presentations, press releases, fact sheets, blog posts, letters, opinion pieces, and other public-facing materials.

- Shepherded CEO profile for *National Journal*.
- Drafted speeches and secured and developed guest blog to build visibility for inaugural international conference.

American Federation of State, County & Municipal Employees

Washington, DC

Blog Editor/Senior Writer

Wrote speeches and scripts for executive leadership. Edited, approved and wrote blog content for national platform. Collaborated with web team to maintain cohesiveness between blog and enterprise website. Developed opinion pieces. Liaised with content experts to ensure message cohesion. Coordinated strategic communications projects.

- Facilitated communications solutions and provided guidance to field communications staff to sharpen writing skills.
- Ensured compliance with policies and procedures and upheld best practices for published blog and social media content to inform members and drive traffic to the website.

Links Media, Rockville, MD

Executive Communications Manager

Provided communication services to support the priorities and mission of the General Services Administration/National Capital Region. Developed and executed leadership communication plan, speeches and digital content for the Acting Public Buildings Service (PBS) Regional Commissioner. Advised senior leadership regarding internal communications and employee engagement programs. Directed, reviewed and drafted supporting collateral, including presentations, fact sheets and other public-facing materials. Mentored junior staff.

- Developed, implemented and evaluated collateral material tool kit for the Regional Office Building Realignment Project, a highly visible, cross-functional team.
- Provided media and event planning, logistics support and event-day management as part of the GSA team to produce the U.S. Environmental Protection Agency Headquarters Naming Ceremony in honor of President Bill Clinton.

AARP, Washington, DC

Senior Speechwriter

Researched and prepared speeches, presentations, talking points, scripts and fact sheets for board members and senior executive leaders, particularly regarding health care, before national and international audiences. Managed materials development for the Livable Communities initiative. Designed communication plans. Coordinated employee communications projects.

- Contributed to front-page *USA Weekend* magazine article that ran in more than 600 Gannett newspapers nationwide.
- Wrote remarks and script for AARP-New York “Listening Tour” launch featuring AARP's Chief Communications Officer and Senior Vice President, garnering extensive regional network and newspaper coverage.

Hager Sharp, Washington, DC

Senior Account Executive

Managed multiple tasks in the firm’s education practice: maintained client relationships; assisted with new business pitches; drafted media materials, talking points, fact sheets, background statements and reports.

- Helped write and edit a major report on behalf of the client, the National Assessment of Educational Progress (NAEP).
- Participated in the report's release (including event-day management) and provided event summary to multiple stakeholders.

National Education Association (NEA), Washington, DC

Speechwriter

Wrote and edited speeches, remarks, fact sheets and opinion pieces for the Association’s president, officers and executive committee. Prepared statements and talking points for press briefings and interviews. Monitored speech reporting system to track speeches and editorial analysis pieces. Evaluated speaking opportunities to meet strategic scheduling objectives. Provided scripting assistance for annual conference.

- Wrote op-ed, “Brown’s Work Lies Unfinished,” to commemorate Brown v. Board of Education; published in Knight-Ridder newspapers.
- Drafted and edited “President’s Viewpoint” column for *NEA Today* on behalf of the Association’s president.

Office of Governor Parris N. Glendening, Annapolis, MD

Speechwriter

Drafted and edited the Governor's speeches and articles in the areas of public health policy, education, the environment, transportation and social policy. Prepared statements and talking points for press briefings and events. Developed and edited media-related communications and PowerPoint presentations. Drafted internal employee communications. Provided event support.

- Wrote Governor's [introductory remarks to welcome former South African President Nelson Mandela](#) during his visit to the University of Maryland at College Park.
- Wrote "Pragmatic Federalism and State-Federal Partnerships" article for *Spectrum: The Journal of State Government*.

Office of Senator Charles S. Robb, Washington, DC

Legislative Assistant

Drafted legislation, testimony, floor statements, fact sheets and decision memoranda. Maintained avenues of communication with constituents and interest groups. Led Legislative Correspondent team in assigned issue areas by editing constituent correspondence content and monitoring timeliness of constituent response. Represented the Senator at meetings, forums and related events.

- Acknowledged by then-Secretary of the Treasury Lawrence H. Summers for work on the New Markets Initiative.
- Conceived, planned and implemented assistance plan to help ease economic transition in the southwestern region of Virginia; highlights of that work garnered regional media coverage.

House Democratic Policy Committee, Washington, DC

Special Assistant

Assisted Executive Director with coordinating policy initiatives for the House Democratic Leader Richard A. Gephardt. Drafted fact sheets and correspondence. Provided research assistance to senior policy staff.

- Coordinated congressional and White House staff policy briefings.
- Represented the Democratic Leader in "The House that Congress Built" program with Habitat for Humanity and other groups to encourage Members to help build homes in their congressional districts. Participated in the "The House That Congress Built" initiative in Northern Ireland. Areas visited: Belfast, Northern Ireland and Dublin, Republic of Ireland. Home-building, lectures and visits sponsored by Habitat for Humanity.